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Supporting Schools in Identifying and Safeguarding the Needs of Disabled Children: the challenges for data collection

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Supporting Schools in Identifying and Safeguarding the Needs of Disabled Children: the challenges for data collection

Abstract

Conceptualisations of disability that emphasize the contextual and cultural nature of disability and the embodiment of these within a national system of data collection present a number of challenges especially where this process is devolved to schools. The requirement for measures based on contextual and subjective experiences gives rise to particular difficulties in achieving parity in the way data is analysed and reported. This paper presents an account of the testing of a tool intended for use by schools as they collect data from parents to identify children who meet the criteria of disability established in Disability Discrimination Acts (DDA). Data were validated through interviews with parents and teachers and observations of children and highlighted the pivotal role of the criterion of impact. The findings are set in the context of schools meeting their legal duties to identify disabled children and their support needs in a way that captures the complexity of disabled children's school lives and provides useful and useable data.

Introduction

Internationally there has been wide concern to develop robust procedures to identify and safeguard the needs of children and young people who are disabled with World Bank, UNESCO, OECD, Eurostat, and UNICEF all developing and trialling survey measures. The World Bank views the collection of disability data as a necessary precursor to the development of provision (Robson and Evans 2003) and cautions against seeing the development of indicators as an end in themselves, providing a timely reminder of the need for "measures" to be clearly linked to purposes. The World Health Organisation has attempted to reflect the multi-dimensional nature of disability making a distinction between body/functions/structures, activity and participation and environmental factors that has been extended to children and youth (World Health Organisation 2007). While it provides a detailed coding system for the functioning characteristics of children (Simeonsson et al 2006) it is cumbersome and struggles to represent personal experience (Imms 2006; Badley 2008).

While global organisations search for a universal series of indicators for measurement, researchers in the UK recognize and debate the ways in which disability can be seen as a culturally situated construct where the effect of impairment is mediated by the supports available in different contexts making it a

politically contested site of activity (Shakespeare 2008). Impact of impairment is therefore given prominence and this foregrounds the importance of the experience of disabled people in the definition. In England as elsewhere definitions of disability and the ensuing duties of organisations are enshrined in a series of legislative Acts and now brought under the Equality Act 2010. The Acts set out the following definition of disability:

A person (P) has a disability if—

- (a) P has a physical or mental impairment, and
- (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities

Paragraph 6 of the Equality Act 2010

The extension of the legal definition to include issues of mental health and medical conditions such as HIV and facial disfigurements highlights the importance of recognizing that “impairment” can only be viewed within the context of its impact. It therefore recognizes the contribution played by the supports that are in place. Its purpose is clear, namely “to protect the rights of individuals and advance equality of opportunity for all” (Government Equality Office 2010): placing a duty on organisations to make reasonable adjustments, either in the ways things are done, to the environment and/or providing additional aids or services.

Duties have been placed on all schools in the UK, irrespective of their status, to develop accessibility schemes, to monitor the impact of their activities on people (children, staff and parents) with a disability and to make reasonable adjustments to their policies, practices and procedures. These duties cannot be met without adequate means for identifying children who meet the definition. This calls for some categorisation based on the subjective experiences of children and their families of the impact of any impairment on daily life. As the purpose of the act is to advance equality there is a need for parity between schools in the means and methods of identification. This paper concerns the testing of a toolkit for schools to use to survey their population. It concerns the challenges in developing “measures” based on contextual and subjective experiences and the relationship between the conceptualisation of disability and the validation process. It takes place in the context of producing a useful and usable tool for schools to use that will enable schools to meet their Disability Equality Duties.

Background

There has been an ongoing concern about the lack of reliable data on disabled children in schools (Read et al 2009; Blackburn et al 2010) and researchers and providers have looked to national household surveys to draw conclusions about prevalence. There have been strong arguments to link the data collection tools to services (Evans and Robson 2003), ensuring that the tool is fit for purpose. This can however, lead to a categorisation of individuals on the basis of a predetermined set of available services, thereby not recognizing the diversity of experience nor individual differences in what constitute helpful supports. This has also in the past led to a circularity in which only those children are identified that can benefit from existing services. The development of provision requires some quantification of the extent of unmet need (Blackburn et al 2010). The Equality Duty also requires Local Authorities and Government to monitor the impact of their activities on disabled children. This requires some coding and categorising alongside qualitative descriptions in order to inform policy and practice decisions. Shakespeare (2008) describes impairment as scalar with services having to define “how much” of a difficulty for administrative and official purposes. Even at a simple level a distinction must be made between those who are and aren’t disabled.

Effectively legislation has now widened the meaning of disability far beyond definitions previously used within the general population and to some extent by professionals in welfare services. This legal definition includes individuals with impairment where the difficulty may be largely invisible to schools (e.g. mental health difficulties or medical conditions where the treatment is effective in offsetting the impact of the condition in the school setting). Adopting a universal approach (rather than targeting particular children) helps to ensure that data are collected from *all* children who are struggling. Schools need to collect information from both parents and children about how that impairment is experienced, and for the data to enable actions based on what supports are helpful for the child to make the necessary adjustments. Lightfoot et al (1999) illustrate the need for both direct and indirect responses to be made with the main difficulty facing disabled or ill children being absences from school and school life compounded by the ways in which this impacted on the relationships with peers together with teachers’ reactions to their difficulties. Mukherjee et al (2000) provide data from parents and teachers that demonstrate the need to assist school staff in gaining and understanding health information, in passing it on to relevant colleagues and co-ordinating the support that is necessary including the emotional support. Moules (2002) makes a strong case

for the involvement of children in this process including where it concerns issues of mental health (Roose & John 2003).

The technical challenges of collecting this data are compounded by the fact that the term disability is not only poorly understood amongst the wider population (Bajekal et al 2004) but also has negative connotations leading people to prefer the use of other terms (Scottish Council Foundation 2005) and notably in children the use of the term difficulty rather than disability (Lewis et al 2005). Research by Watson (1999; 2002) illustrates the ways in which disability is a fluid concept for many young people in that their identity is not based around an impairment, indeed they (and their families) do not see themselves as disabled or only with respect to certain contexts. The disclosure of disability is therefore a sensitive issue and one that requires schools to establish a positive ethos with parents where there is a belief that this information will be used to enhance participation.

The survey of disabled children reported here was the first to be developed to provide reliable data for schools and local authorities to report to Government. An integral part of the survey concerned the testing of measures of impact together with establishing the validity and usability of the tool.

Reporting on Impact

There has been a call for comparability between measures of disability (Read et al 2007) and therefore what constitutes an impact on “normal day to day activities”. This is increasingly interpreted in relation to areas of child functioning. Litigation in the US has defined major life activities as ones that are central to most people’s daily lives (Pullin 2008) but arguably the centrality of an activity is not fixed. Parents have varied expectations of their children and of family life, and the presence of impairment can have a differential impact.

Impact can be a tricky aspect for parents to report on as there may well be a cyclical element to it. Closs (2000) points out the overlap between medical conditions and disability and in particular the grey area between the two, in which many children may not be really ill or really well. She lists the following possible contributing factors which may result in under-achieving through: feeling under-par; being absent from school; requiring treatment or medication in a way that disrupts the school day; feeling anxious and uncertain about the prognosis or course of the condition; feeling

different from others because of the treatment or the condition itself. Measures of impact therefore need to reflect the fluid and dynamic nature of the experience.

In England the Family Resources Survey (FRS) provides a list of eight areas of functioning but makes no reference to mental health. The focus is very much retained on individual difficulties thereby neglecting social and environmental contextual factors that may be contributing to the child's needs. This focus is retained in the development of NI54, a Government measurement of parent satisfaction with services for disabled children. Here, however, reference is made to depression and behaviour as well as adding categories of eating and drinking, palliative care and autism. In order to provide comparative data these items were also used in the survey reported here.

Neither the FRS nor NI54 attempt to define what might constitute a "substantial" impact or make reference to the fluid and dynamic nature of the experience. The current survey therefore enabled parents to indicate using a continuum of descriptors of how the impairment or condition was experienced. A five point scale was developed and trialled (see Porter et al 2008) prior to further clarification for this final testing stage. It enabled parents to indicate that the impact could be described as offset by medication; minor or trivial; occasional but regular stopping or limitation of activities; frequently affecting daily activities; or having an impact on almost all activities. The scale enabled responses to reflect the way that routines and favoured activities vary between families.

Validation

Surveys typically confine their validation measures to aspects of internal design and analysis and there is a role here for the use of multiple indicators such as having seen a professional, having a diagnosis, experiencing a long term difficulty. However validation is not simply about confirming the presence of a longstanding impairment as it is the impact of impairment which forms a pivotal part of the designation. This can bring perceived disparity between the judgements of impact by parents of children with identical impairments and in consequence whether or not they meet the DDA definition. Validation methods therefore need to respect the cultural and other differences between families, schools and communities that mediate the experience of that impairment. Notably therefore it was decided that the researchers would not simply ask schools to confirm the presence or absence of disability (thereby negating the purpose of having a parental questionnaire) but would investigate returns that

were surprising to schools and scrutinise these more closely. This scrutiny included an analysis of the barriers and supports that are existent in school and that may be present or lacking at home, and observations of pupils' engagement in school. Parents were also interviewed about their interpretation and responses to the questions.

Usability

If the survey is to provide a universal measure and provide data from all parents then it is important that the process is manageable for schools and the guidance transparent and easy to follow. Previous research illustrates variation in the way schools interpret and record SEN data (Daniels and Porter 2010) and therefore a further element of usability concerns the consistency with which schools interpret and report on children identified as disabled.

The following report further examines data collected as part of a Government funded study to test out a parent survey which formed part of a toolkit for schools to use to collect and report on disability data in the light of its probable inclusion in the Annual School Census. The aim was to assess whether the toolkit resulted in the generation of robust and consistent data that could reliably inform school returns for the Annual School Census. The toolkit also included methods for collecting pupil views on the barriers and supports to learning but these are not reported here.

Procedures

The Parent Questionnaire

Drawing on developmental work with schools (reported in Porter et al 2009) a questionnaire was designed that used multiple indicators and made reference to difficulties as well as disability. It comprised 10 key questions, of which nine were closed questions requiring a simple tick response. Information was provided about how the collated responses would be used and who would have access to the data. At the start of the questionnaire parents were asked to consider if their child experienced difficulties in aspects of schooling and life in and outside the home. They were asked if their child had a serious accident or trauma and if their child had a physical or mental health condition, impairment or difficulty and further if it had gone on for a year or more (or was likely to). In both instances examples were given. At this point parents who had answered yes to any of the previous questions were invited to state if their child had seen a professional and what diagnosis was given. Parents were asked about the impact of the activity and the nature of their child's

needs (using a list derived from the NI54 descriptors). Parents were asked about medication, physical aids and diet. They were also asked about the support that their child found helpful (responses to this question are not reported here). The form provided an opportunity for parents to indicate if they wished to speak to a member of school staff, and to state if there was anyone they would prefer not to have access to the information they provided. They were invited to be interviewed by the research team about the process of completing the form. The form was made available in paper and electronic form.

Sample

Local Authorities nationwide were invited to nominate between 5-10 schools and twelve were able to meet the project deadlines including unitary (4) county (3) metropolitan (3) and Greater London Authority districts (2). They nominated 52 schools using a variety of approaches (some authorities approached particular schools; some put out a general call for responses; and one authority nominated schools without their prior notification) of whom 49 returned data for this part of the project. The LAs were situated in inner city (8 schools), urban (18 schools) and rural (23 schools) locations and represented the range of children receiving a statement of special educational needs with between 38%-51% (average for England is 47%) of those children attending mainstream provision (DCSF 2009). Of the 49 schools, 25 (51%) were for primary aged children 15 (31)% secondary and 9 (18%) special schools. The latter included one school for pupils with Behaviour, Emotional and Social Difficulties (BESD), two schools that were designated for pupils with Moderate Learning Difficulties (MLD) and six that were designated Severe Learning Difficulties (SLD). All but one school explicitly also provide for pupils with Autistic Spectrum Disorder (ASD). In addition the sample included a range of resourced mainstream provision, including one primary school with a unit for children with a hearing impairment, another with provision for children with ASD, and a third for severe Language and Communication Difficulties and three secondary schools with additional special provision, one with a unit for pupils with PMLD, one resource provision for pupils with Specific Learning Difficulties (SpLD) and a third with integrated MLD and SLD provision.

Schools received a full information pack and briefing meetings were set up in 6 Local Authorities. A podcast was made for schools where staff were unable to attend and posted on the project website. Schools were invited to provide information that would

enable their tools to be individualised through the inclusion of the head teachers name on the letter to schools and the name of the person who would be receiving the questionnaires and ensuring that responses were treated confidentially. Schools chose their target year group(s). Of the 25 primary schools, three schools opted to collect data for all year groups, 16 selected a single year group (the most favoured being Year 3) and six schools chose two year groups. The secondary schools all chose a single year group (Year 7 being the most favoured) and one school elected to survey a single tutor group. The special schools mirrored the primary schools in that three chose to survey the whole school, one chose two year groups and the remaining five schools selected single year groups.

Schools were supplied with all materials (questionnaires, personalised covering letters, reminder letters, and return envelopes) and given a 2-3 week timeframe in which to encourage returns.

Schools were asked to review their returns following a simple sifting process, with guidance to identify pupils who met the legal definition and to complete a simple online form ONLY entering data about those pupils who met the criteria. Schools were asked to return all completed questionnaires (using prepaid and addressed envelopes) to the research team for the data to be entered online for analysis by the research team using the same sifting process and thereby testing the algorithm for identifying disabled pupils against those entered by the schools and isolating any internal discrepancies. Schools were subsequently given a data base of these returns for their records.

Validation Visits

Validation visits were made to 31 schools: 12 secondary, 13 primary and 6 special. Staff responsible for collating the returned questionnaires were interviewed about the use and usability of the questionnaire. The interview included questions about process of gathering data, the sifting and recording of the data, the use and usefulness of the data it generated, how the process compared with their existing systems of gathering disability data and their views on systems and structures for the future, given the government intention to include a disability question in the Annual School Census. A short paper version of this interview schedule was also sent for completion to schools that were not visited.

Where possible during the school visits, the research team observed 1-6 children of parents who had returned the questionnaire including those who provided information that was a surprise to schools. Researchers carried out short narrative observations of 1-2 activities over a 40 minute period, noting in particular the level of participation and engagement of the pupil (adapted from Laevers et al 2002), any barriers and supports to learning and any areas of need that were noticeable during the session.

Parent Interviews

Twenty-five parents were interviewed about their experience of completing the questionnaire and any uncertainties or confusions they encountered, sampling across children who did and did not meet the disability criteria.

Results

The 49 schools sent out 6,208 parental questionnaires, 2382 (38%) primary, 3426 (55%) secondary and 400 (6%) special). The overall return rate was 41%, with 2537 questionnaires returned to schools, 72 of them online. Table 1 shows that the average masks considerable differences between schools with secondary schools provided both the highest (83%) and lowest (5%) response rate.

Insert table 1 about here

Table 2 shows the split by gender and by phase of schools of the responses. Boys were over-represented in the returns from special schools, reflecting the national census data for special schools (DCSF 2007).

Insert table 2 about here

Children Who Met the Disability Criteria

In total 270 children were identified who met the legal disability criteria, 59 in primary schools, 54 in secondary and 157 in special schools, a prevalence rate for the returned sample of 5% in both primary and secondary schools and 80% in special schools or taken together 11% of the total sample. This is slightly higher than the 7% reported by the Government (Cabinet Office 2005). The gender divide in primary schools was more uneven (72% boys and 38% girls) than secondary schools (46% boys and 54% girls). It is unclear why prevalence rates for boys are higher in primary

schools. National figures for disability are generally only slightly higher for mild disability in boys although substantially higher for severe disability (ONS 2004) and as shown in Table 3 this is reflected in the returns of special schools.

Insert table 3 about here

Professionals and Diagnosis

The presence of an impairment forms a key part of the legal definition of disability and the majority, 264/270 (98%) of parents reported that they had seen a professional. Of the six parents who hadn't, four were in special schools and it is therefore highly probable that they would have seen a professional prior to entry. Parents were asked what the condition was that was identified or diagnosed and 93% provided this further information. One of the most prevalent diagnoses was being on the autistic spectrum: 109 children (41% of those providing a diagnosis) had this diagnosis although in many cases it was one of several. 29 children (11%) were diagnosed as having ADHD, 29 (11%) asthma, 19 (7%) epilepsy, 13 (5%) cerebral palsy and 11 (4%) Down Syndrome. Generic terms were frequently used to describe the diagnosis the most commonly used was global developmental delay which was used for 25 (9%) children. For seven pupils the assessment process was ongoing and for a further five the diagnoses were uncertain, with one parent stating they could not remember and another that the diagnosis was private.

Impact on Daily Life

A significant and pivotal aspect of the criteria is that the impairment or condition has a substantial (i.e. not trivial) impact on daily life. In some cases the impact was felt on almost all activities. This included 45% of the pupils who met the definition in special schools, 13 % in secondary schools and 27% in primary schools.

Insert table 4 about here

In mainstream settings, as shown in Table 4, the impact was more likely to occur at particular times and situations, although notably the distribution across categories of impact was more evenly spread in the primary school.

Parents Description of Need

Perhaps unsurprisingly the largest category of need was in the area of learning (82% of children) followed in order of size by communication (75%), and behaviour (61%)

and these three areas of need were the dominant ones across all three phases of education. Notably however, as shown in Table 5, mental health difficulties and difficulties with eating and drinking are also prevalent areas of need amongst the identified pupils in secondary provision.

Insert table 5 about here

Many children had multiple areas of need with 8 children having a total of 11 identified areas of need. As might be expected pupils in special schools were more likely to have multiple needs and pupils in mainstream having a markedly higher proportion of children with a single area of need.

Insert figure 1 about here

Level of need was not a true or exact indicator of impact and not all of the children with identified areas of need met the legal criteria for disability as parents indicated that there was no substantial impact, including a child whose parents identified nine areas of need. Eleven pupils had five or more areas of need, three of them were placed in primary schools but the majority were in special schools. Their parents had either reported that the impact was trivial or small (8 instances) or that there was no difficulty (2) or left the question blank (1).

Parent Feedback about the Form

In order to gain further insights into the validity of the data and the usability of the questionnaire, twenty five parents were interviewed, twenty one had entered details of a diagnosis and eight of these reported an impact. A further two had reported an impact and provided no diagnosis although one child was seeing a professional. One parent had replied no to every question and two had identified single elements of difficulty in the opening questions. In terms of disability eleven met the legal criteria and fourteen did not.

Parents reported that they found the questionnaire very usable and clear. They raised no concerns or qualms about their involvement, their child's involvement, the questionnaire or the interview, although one parent was confused as to the origin of the questionnaire. Two parents commented that the questionnaire was difficult to complete when their child was affected by more than one condition and one said that

their tendency was to complete the questionnaire for only one of the conditions as it was difficult to keep both in mind while answering the questions and one parent suggested separate questionnaires for physical and mental conditions. In contrast the parent of a multiple-disabled child did not make this observation. The following issues were also raised by individual parents: one parent commented on the advantage that the online version of the questionnaire had in filtering the questions for the parent so that they didn't have to sift through what was/ was not applicable themselves; one parent wasn't sure if completion of the questionnaire was compulsory or voluntary but felt that it was compulsory; one parent said that they had found the questionnaire daunting initially but then found it accessible once they had started; and one parent found the process of completing the questionnaire upsetting.

While the parent interviews were primarily to test the usability and the clarity of the questionnaire, interviews with parents about the process of completing the questionnaire included validation of the responses to each question. This did not reveal further significant information, suggesting that the questionnaire in itself provided full and sufficient responses.

Usability

In addition to collecting data from parents, interviews were carried out with key staff on the use and usefulness of the data collection process and schools were invited to return evaluation forms. Taking these together, feedback was received from 45 schools (90% of the sample). Most schools (81%) found the process of distributing and gathering data from parents unproblematic although 16% commented on having insufficient time. Almost half the schools (20 out of 45) opted to alert parents before sending out the questionnaire with 13 schools reporting sending a briefing letter or included information about the questionnaire in a school newsletter. Other briefing/preparation methods included mentioning the questionnaire in a school assembly, and displaying the questionnaire at a parents' evening. Schools went to considerable lengths to try and ensure a good return: 31 schools sent the reminder letter home with students; and other schools used a variety of creative methods to remind parents, for example using a text messaging system, and posting up reminders on a daily bulletin board in the playground.

Feedback from schools on the sifting process

The reaction from schools about the process of sifting through the questionnaires and identifying students judged by parents to have disabilities was overwhelmingly

positive. 33 (of the 45 schools that returned questionnaires) found the process undemanding and feedback included, “Easy”, “Very straightforward – really liked the guidelines”, “Fine, no problems.” The only concern raised by schools related to time demands: five schools (out of the 45) commented on this, e.g. “Time consuming but interesting”, “... lengthy process.”

Schools use of the data

A significant number of schools indicated that they found the data useful with two thirds of the schools (30 out of 45) indicating that they intended acting on the information that emerged from the survey or that the survey added to data already collected. Interestingly, this included four of the seven special schools (where it might be anticipated that staff would be knowledgeable about the range and impacts of children’s difficulties), one of whom commented, “We get a lot of information from Statements ... but this is much more detailed than current SIMS data.”

The data revealed new information for schools and the occurrence of surprises were distributed fairly evenly across the three types of school: four out of 14 secondary schools; eight of the 23 primary schools; and three of the eight special schools reported surprises. Most of these related to students who were identified as disabled by parents but whose difficulties were not recorded in this way by schools; and these difficulties tended to be health related (e.g. difficulties associated with asthma). The exception was in special schools, where two of the three surprises related to parents’ judgments of the impact of their child’s difficulties which contrasted to the schools’ views.

Twenty schools (out of 45) indicated the action they would take as a result of the data collected from the parental questionnaire. Five schools anticipated using the data as an additional check (e.g. to ensure that the schools’ current records – including medical records - are comprehensive); five schools will use the data to inform plans for targeting or monitoring support for students; and four schools planned to contact parents to follow-up issues they had mentioned. Two schools commented that this exercise would contribute to better data collection in future: “This needs to be included in what we are already doing”; and “We will improve our data collection as a result of this survey.” Another two schools commented that the data would help identify students’ difficulties, for example, “... to highlight any undiscovered issues mentioned by parents.” Other matters raised by schools included using the survey information to liaise with other professionals about health problems; to update

information without targeting students suspected of having DDA status; to inform pastoral/SEN planning; to contribute to the School Development Plan and Disability Scheme; to inform possible CPD events; and using the information to review and update information on students' Statements. A member of staff in one school considered that the data added to the "whole picture" by increasing specific knowledge of students' difficulties, and in similar vein, another member of staff commented, "It will help the school to improve [our] response to diverse needs."

Observational Data

A further source of evidence was provided through observations of 42 children in school, 37 of who could be matched to the database of parent returns. There were 13 individuals where the response to the parental questionnaire surprised the school and data concerning these pupils were given particular scrutiny. In particular we looked at the levels of participation assigned by the researcher on a scale from 1 (shows little or no involvement or activity) to 5 (shows high and sustained involvement) during the observed lessons. Although this was an approximate measure it served to indicate how well engaged in the lesson the pupil was and therefore whether or not schools might have concerns because the level of involvement was very low or whether they would be assured by high levels of participation.

There were 29 observations of children whose parents' reports on the questionnaire did not surprise the school. Of these, five were children whose class participation was judged to be problematic (scored as 1 or 2 the five point scale). All of these were cases where very visible conditions were reported e.g. ADHD, SLD/PMLD, and ASD, one in special school and the others in primary schools. The remaining pupils were however showing good levels of participation in the learning opportunities offered to them.

Children where the response to the parental questionnaire surprised the school

Of the 13 "surprise children" there were five children whose class participation could be judged to be problematic. They were scored as 1 or 2 on a five point scale, that is they were not participating in an activity and showed little awareness of what was going on in the classroom, little receptivity to the learning opportunities on offer or they showed small fleeting moments of involvement or participation. Of these five there four cases where the school was surprised that the parents did not report the

same order of difficulty observed in school including one child who did not speak at school but did so at home. The fifth child was a case where the school was surprised and had not recognised the barriers to progress. The child had Spina Bifida which was unknown to the school. As we can see from the details in figure 2 parents had important information to share with the school.

Insert figure 2 about here

Observations on the remaining eight surprise children suggested that they were engaged in class activities. Seven of the eight showed good levels of involvement, the activity appeared to have meaning for them and they were engaged, sometimes intensely so. The eighth child showed more or less sustained activity (although it lacked intensity). These then were children who, at least on casual observation, would not be a cause for concern for the school. However there were two cases where schools would have benefitted from more information as both led to absences at school, one through asthma and the other severe migraine. These data suggest the need for a question which probes impact of a disability on school attendance.

Overall the observational data suggested that schools are aware of difficulties that give rise to problems with participation in class. However the parental questionnaire surfaced experienced difficulties that remain invisible to the school and have hitherto been unreported. They also revealed cases where there was no difficulty experienced outside the school.

Reliability in the Use of the Data

An important element of reporting on disability is to facilitate consistent interpretation of the returns across schools. To this end schools were provided with guidance on how to identify pupils that meet the legal criteria by considering responses to combinations of questions. Thirty six schools completed the online summary census form and also returned their questionnaires, providing data drawn from a sample of 1,665 pupils.

The schools identified a total of 318 disabled pupils with 93% of the children also identified as meeting the criteria by the research team. However, schools included an additional 110 children not identified by the research team. Notably under a third of

the additional 110 children had a reported impact, suggesting that some schools had not taken impact as pivotal in meeting the criteria. Of the 36 schools included in this part of the sample 16 had reported differences, but in the majority of cases these were limited to four children or less. Closer scrutiny revealed that five schools (three primary, and two secondary) accounted for over three quarters of the additional children. In many cases it was not clear why schools included those additional children. For example not all the additional children had parental reports of difficulties experienced at school or of difficulties in learning and/or behaviour, so it is unclear whether schools used their own existing knowledge to enter these pupils.

On the one hand the degree of difference between schools' entries on the census and that of the research team is surprising especially given that schools reported the sifting to be an easy and straightforward process. However four of the five schools with the greatest disparity were not able to attend briefing meetings and may therefore have been unclear about the rationale for entering data only from children that met the legal criteria or perhaps more likely, that despite the guidance they were unclear about the pivotal role of impact and which children met the criteria.

Discussion

The aim of this study was to assess whether the survey tool resulted in the generation of robust and consistent data that could reliably inform school returns for the Government's Annual School Census. This is however a sensitive and often poorly understood area in which to collect data, one that has challenged both the national and international community. The legal definition of disability in the UK gives rise to the need for information concerning both impairment and impact on daily life thus placing the onus on schools to collect this information from parents, collate and analyse returns and report on the data. Challenges exist at each stage of the survey process.

Schools vary in the ease with which they are able to elicit questionnaire returns from parents and therefore the extent to which they are able to represent the needs of all children in the ensuing data. Checking the robustness of the data is also not straightforward. Validation cannot for example be confirmed simply by asking schools to compare the returns with their own registers for disabled pupils as previous research has pointed to the way in which schools and LA conflate disability and SEN (Mooney et al 2008). Additionally children that had been invisible to schools could be

excluded by this process of validation. Comparisons with other survey data can provide some insights into whether some groups are over or under-represented.

If the survey data is to provide useful and usable data for Government there also needs to be parity in the way that it is reported. Previous research has illustrated the variation in the way schools interpret and report SEN data (Mooney et al; Daniels and Porter 2009; Lewis et al 2009). Although in part this reflects a whole range of complex factors within and across Local Authorities and schools it could also reflect a lack of specificity in the way the data are interpreted and reported. Given these challenges it is important to interrogate the data to ask:

1. Given the low return rates, how do these data compare to other surveys?
2. Did parents of both disabled and non-disabled children return the questionnaire?
3. Is there evidence that some children may have been falsely included or excluded?
4. Did schools report accurately on the data?

Comparison to other surveys

Return rates were quite variable across schools although the overall average, minimum and maximum was equivalent to other surveys carried out under similar conditions (Porter et al 2008; 2009). Most schools reported that the process of distributing and gathering data from parents to be unproblematic but varied in the extent they were able to adopt strategies that are known to increase response rates. Many schools for example did not manage to brief parents, a strategy that research suggests increases return rates (Heberlein & Baumgartner 1978; Kaplowitz et al 2004). A number of schools said that there was no time for this and in one instance that they had no mechanism for doing so. Schools went to different lengths to remind parents but most sent out the provided reminder letters and one school used text messaging systems instead, a more efficient system for contacting parents. There was however no clearly discernible pattern between the use of strategies and actual return rates. It is likely that there is a more complex set of predictors. Taking the schools with the lowest rates, these were more likely to be in areas of deprivation with higher proportions of children eligible for free school meals. This is a particular concern given the two way relationship between poverty and disability in children “with a close geographical dimension” (IPPR 2007) so that children who are particularly disadvantaged may be under-represented in Local Authority and Government statistics through low return rates.

Discussions with schools suggested that questionnaires were not returned from all parents of children with a disability, although many schools did not keep a comprehensive list of children with a disability (and often included all children with SEN on the list) and equally some returns were received concerning children for whom they had no previous knowledge. Given these uncertainties it is important to examine through other survey data whether parents of disabled children were more or less likely than other parents to return the questionnaire, namely whether the prevalence rates were representative.

Comparisons across survey measures to check the impact of low response rates on the robustness of the data need to be undertaken cautiously (Read et al 2007). The FRS, one of the few surveys to use a DDA definition of disability, used different classifications for impact and found a prevalence of 7.3% of those who experienced a “DDA defined disability” with a higher rate for boys (8.8%) than girls (5.8%) and with the most commonly reported difficulties being in aspects of learning and communication. The highest rates are found in groups with the lowest income. These figures were based on a return rate of 62% but with some ethnic groups under-represented. The prevalence rate in this survey was 11% (5% of mainstream children), slightly higher than the reported average. There was a higher prevalence rate amongst boys (13% of the sample) compared to girls (8%) and again in parallel to the FRS study the most prevalent areas of need were learning and communication. (Ethnicity data are not available for this sample.) The method of sampling in the study reported here relied on LA nominations which may well have provided some skewing of the sample as illustrated by the very high proportion of children whose parents reported ASD and the slightly higher proportion of boys to girls. In other respects however there is similarity to the data despite the lower return rate.

It is also important to look within the data for evidence that some children had been falsely excluded. Previous studies have highlighted how children with mental health difficulties have been under-represented (Porter et al 2008). The Mental Health Survey suggests one in ten children aged 5-16 to have a clinically diagnosed mental disorder (Green et al 2005). This figure exceeds that quoted for all children with a disability of around 7% (DfES/DRC 2006). Notably Grant & Hamlyn (2008/9) in the returns for their study of services for disabled children found 15% of 16-19 year olds suffer from depression. In the light of this under-reporting this survey tool made

explicit reference to mental health needs in the opening phrasing of all relevant questions. Over 1 in 5 children who met the disability criteria were described by their parents as having anxiety or depression. Notably almost a third of children identified as disabled in secondary schools had a mental health need. Few however were recorded as having mental health needs only, with the vast majority having those needs in combination with others. This is difficult data to evaluate. Green et al (2005) report an overall incidence of clinical mental health difficulties in children 5-16 to be 9.6% but this includes children with conduct disorders who would be represented elsewhere in our survey. Looking just at emotional disorders the national prevalence is 3.7% with a slightly higher incidence in girls. This group is under-represented in this survey as it formed just over 2% of our sample. Disclosure by children that they are struggling with aspects of school life have a higher reported incidence than those reported by their parents (Porter et al 2008) and it is probable that children provide a more transparent account of their emotional difficulties than parents, reinforcing the importance of collecting data directly from children as well as parents.

Parent comments at interview confirmed the sensitive nature of these data and it is possible that parents were reluctant to indicate that their child had a disability despite acknowledging a number of areas of need. In this survey, unlike the FRS, impact was reported separately to identifying areas of need and the former was taken as a pivotal indicator of whether the child's impairment was experienced as a disability. A number of children in this survey had parental reports of multiple areas of need but limited rather than substantial impact. This was illustrated by the parents of one nine year old pupil who identified 12 (out of 14) areas of need yet had indicated that the condition only occasionally interfered with daily life. Given that the DDA definition refers to a substantial impact, these children could not on the basis of parental returns be judged as meeting the DDA criteria. Clearly there is not a simple equation between numbers of areas of need and impact on the child. Three issues are raised here; firstly that impact depends on the type and amount of support that is required and available; secondly that there are cultural differences in the way that impairment is experienced within the home and school; and thirdly that there are sensitivities around disability that make disclosure around impact less likely.

Disability and Impact

The presence of eleven pupils in both mainstream and special school settings whose parents reported no impact despite identifying a number of areas of need raises important issues about the identification of need and the level of support that is

provided. A health condition that flares up creating a number of areas of need but on a relatively infrequent basis may be managed through a short absence from school and may be experienced as having limited impact. Other pupils may have an impairment and require support in many areas and where this is provided again experience limited impact. This is well illustrated by the following quote from a parent whose child is represented in this group:

He has a brilliant support team at his school. This enables him to participate in all subjects. We continue to work at home via interaction from school. Parent of a 17 yr old in a special school

Where reasonable adjustments are made the child ceases to experience disability. However there are also important cultural differences between families that mitigate the experience of a disability. Routines and favoured activities vary between families. Parents have different expectations of their children and of family life, and the presence of impairment makes a differential intrusion into daily life. The complexity of family life and its attendant pressures mediate on the ways in which difficulties are experienced. Parents can therefore be differentially placed to make adaptations and accommodations. This can bring about disparity between the judgements of impact by parents of children with identical impairments and in consequence whether or not they meet the DDA definition.

Ms lack of hearing does not affect her at all. The only time it may be difficult is if lots of people are talking at once, or not facing her. People may have to repeat things to M, but we really don't feel this is a disability.. Parent of a 14 yr old in secondary school

Children were therefore excluded from the data because their parents did not consider the difficulties to impact significantly on daily life and where school and home were able to adjust to the child's needs. Conversely, the questionnaire also revealed some children whose needs were invisible to schools where reasonable adjustments had yet to be made to enable their full participation in school life.

The third issue to be raised with respect to the data are children excluded through non-disclosure by parents. Sensitivities towards a mental or physical health condition can make disclosure an uncomfortable event and the interview data highlighted that this can be a difficult area for parents to consider. Disability is not a neutral term and

can elicit sensitive and emotional responses. The Scottish Council Foundation (2006) report highlights how fear of discrimination, as well as embarrassment and pride also contribute to under-reporting. There are additional issues with respect to children. Their functioning and learning may be constantly changing (Langlois 2002) and there may be uncertainty about the trajectory of development, particularly in younger children, and a particular reluctance to assign a descriptor to a child that pre-judges the longer term consequences. For older children there may be important issues and sensitivities around self-image and self-esteem. Research by Watson (1999) illustrates both the ambivalence with which teenagers may use the term disability and the contexts in which it is deployed. This research also points to the importance of respecting young people's privacy. As one parent reported:

B likes to keep this all private, her teachers are all aware and they are really good about it.

It is important therefore that schools have systems in place to protect confidentiality. Their effectiveness rely on the trust of parents and pupils that the information will be used to the benefit of their child and that it will be treated sensitively.

Reporting on the Data

The final task for schools was to collate and report on the data. Schools were given specific guidance on how to sift the returned questionnaires and analyse the information to identify who met the legal criteria of disability. They were provided with a brief online form that was designed to emulate the process of reporting back to Government details of those children who were disabled thereby testing the parity between schools in the reporting of this data. Schools reported that they found the guidance easy and straightforward to follow and 80% of schools returned this data although in one Local Authority the adviser chose to input the data from four schools. Around 60% of the schools entered data correctly following the algorithmn provided but the rest of the sample had one or more mismatches in the data. Closer analysis however revealed that a handful of schools (14%) accounted for the majority (over 80%) of mis-reported children. On the one hand this is not surprising given the complexities of understanding the term disability. In particular it appeared that some schools failed to take impact as pivotal and in consequence included children who would not meet the legal criteria thereby treating parental reports of their children's experiences of impairment differentially to other schools. Schools who did not attend

a face-to-face briefing were overrepresented in the group. This reinforces the importance of enhanced briefing and improved understanding of disability as distinct from impairment.

Future Arrangements

Schools in this study had access to a range of formats to guide them: schools were briefed in regional meetings; they were sent written material in the form of guidance and a checklist; and they could watch a podcast. Schools reported that they found the “checklist” particularly useful – this distilled what they had to do but gave relatively little by way of explanation which was provided in more detail in the accompanying guidance. It is quite possible that the sifting and recording task was delegated as a number of schools have data managers. This has implications for who takes part in the briefing process as well as for confidentiality. The procedures adopted in this study underscored the importance of assuring parents of confidentiality. The assignment of a named person to collect and analyse the data provides parents with a point of contact for raising issues and concerns.

As schools already collect data from all parents on admissions this timing serves to offset the disparity across schools with respect to return rates. However parents may feel less confident in talking about their child’s difficulties before they have built a relationship with the school. They may in particular not wish to create a self fulfilling prophecy nor put their child’s place in jeopardy. This issue therefore needs to be handled with sensitivity and be embodied in a wider agenda of the schools response to diversity and difference. The school response to diversity will not only impact on parent responses at admissions but also later when the data will need to be “refreshed” during the course of attendance at school. Schools routinely ask parents to let them know about changes in address, contact details and medication. However asking about disability requires more precision. Where schools are relying on data managers they need to ensure that they have appropriate briefing and are aware of the confidential nature of the information.

Conclusion

Collecting data on disability has proved both a challenge for researchers and for schools and this has been reflected in the overall response rates of this study. We have highlighted our concern that the lowest response rates were achieved by schools in the poorest areas so that the children who are particularly disadvantaged may be under-represented. The data also suggest that children with mental health

difficulties may be under-represented in our returns, particularly where there is no other disability. Despite these areas of under-representation, the survey revealed pupils whose difficulties had hitherto been unknown to schools. While prevalence rates need therefore to be viewed cautiously the survey proved a practical and useful tool for schools to use to collect disability data. It surfaced however a number of important issues about the way disability is understood and reported.

The data have illustrated the ways in which disability can be seen as a culturally situated construct where the effect of the impairment is mediated by the adjustments and supports available in both the home and school setting. Two levels of responsiveness can be identified: the first being that which exists between the school and the national culture which results in a local situated understanding of the nature, extent and implications of impairment and disability; the second is that which operates in the interface between a particular child and the school and or particular teachers. This conditions the way in which the school and or the teachers' attention is directed towards or deflected away from the nature, extent and implications of the barriers to progress that may be experienced by the child. The availability of supports impact on whether a child is disabled or not. A child with a number of different areas of need may therefore only occasionally experience an impairment as a disability, another with a single area of need may experience the impact daily. This creates an unusual and fluid context in which to collect and report data. As schools learn from children and their parents about the ways in which they can best be supported fewer children will be reported as disabled. Moreover schools will become more sensitive to the needs of children whose coping strategies have enabled them to remain invisible to schools. It is therefore important data to collect and not just for schools but also Local Authorities and Government whose policies and procedures can have an adverse effect on the daily lives of children.

While this report has focussed on data supplied by parents, pupils also have a key role to play in providing schools with information about their support needs. In particular it is likely that with respect to mental health issues they provide important insight into their daily experience but that a standard questionnaire or other survey instrument may not always be the best format for eliciting this information. It is likely that this will require a more creative approach especially where pupils are less articulate or reticent to speak. As with the parent questionnaire, schools will need to adopt a universal approach as gathering the views of only known disabled children is likely to ignore the needs of some children who are struggling. Gathering the views of

selected pupils also places undue emphasis on individualisation of need and fails to recognize that changes made with respect to specific children are often to the benefit of all.

The challenge of uncertainty, fluidity, and contextuality in conceptualising disability creates a complex dynamic that could also easily, and worryingly, result in the homogenisation of the experience of disability (Davis and Watson 2002), where children are slotted into categories based on the degree or type of 'reasonable adjustments' that are required. The effectiveness of the legislation depends in part on schools understanding the pivotal role of impact and being informed about this in the analysis and reporting of data. In particular schools need to understand the ways in which children deal with different health conditions in school as this is central to ensuring that schools are well placed to make reasonable adjustments and ensure equality of opportunity. Collecting this data appears to be best undertaken at admissions to ensure that information is gathered on all children but that this data is updated to ensure that schools are aware of late onset difficulties including those relating to mental health. The sensitivity of these data highlights the need for schools to be proactive in assuring parents and children of the ways in which these data will be used and the steps will be taken to respect confidentiality. Schools need to convince parents of the "trade- off between the utility and the consequences of classification" (Pullin 2008), that adjustments will be sensitively made and social justice achieved.

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School Level	Average return rates	Minimum return rate	Maximum return rate
Primary	51%	27%	71%
Secondary	35%	5%	83%
Special	49%	31%	75%

Table 1 : Return Rates by School Level

School Level	Boy	Girl	Missing Data	Grand Total
Primary	637 (52%)	582 (48%)	3	1222 (48%)
Secondary	531 (47%)	586 (52%)	2	1119 (44%)
Special	140 (71%)	56 (29%)		196 (8%)
Grand Total	1308 (52%)	1224 (48%)	5	2537

Table 2 : Pupils by School Level and Gender

School Level	Boy	Girl	Missing Data	Grand Total
Primary	38 (64%)	21 (36%)		59
Secondary	25 (46%)	28 (52%)	1	54
Special	112 (71%)	45 (29%)		157
Grand Total	175	94	1	270

Table 3 : Disabled Children by School Level and Gender

Q6 Overall how does this affect your child in their daily life?	Primary N=59	Secondary N=54	Special N=157	Grand Total N=270
There are particular times and situations when activities are regularly stopped or limited because of the difficulty	23 (39%)	33 (61%)	48 (31%)	104 (39%)
It frequently affects a number of daily activities	20 (34%)	14 (26%)	38 (24%)	72 (27%)
The impact is felt on almost all activities every day	16 (27%)	7 (13%)	71 (45%)	94 (35%)

Table 4: Impact by School Level

Q7 How is your child affected... Please tick any that apply.	Primary N= 55	Secondary N= 42	Special N= 157	Grand Total N= 254
a) Mobility: getting around in or outside the home	23 (42%)	14 (33%)	74 (47%)	111 (44%)
b) Hand function: holding and touching	21 (38%)	4 (10%)	49 (31%)	74 (29%)
c) Personal care: has difficulty washing, going to the toilet, dressing	28 (51%)	7 (17%)	105 (68%)	140 (55%)
d) Eating and drinking: has difficulty eating or drinking by themselves or sickness or lack of appetite	17 (31%)	12 (29%)	54 (34%)	83 (33%)
e) Incontinence: has difficulty controlling the passage of urine and/or faeces	19 (35%)	5 (12%)	59 (38%)	83 (33%)
f) Communication: speaking and/or understanding others	37 (67%)	15 (36%)	139 (89%)	191 (75%)
g) Learning: has special educational needs	36 (65%)	19 (45%)	153 (97%)	208 (82%)
h) Hearing	12 (22%)	3 (7%)	16 (10%)	31 (12%)
i) Vision	7 (13%)	1 (2%)	40 (25%)	48 (19%)
j) Behaviour: has a condition that leads to the child being hyperactive or having a short attention span or getting frustrated or behaving in a socially unacceptable manner	37 (67%)	16 (38%)	113 (72%)	166 (65%)
k) Consciousness: Has fits or seizures	3 (5%)	1 (2%)	30 (19%)	34 (13%)
l) Diagnosed with Autism, Asperger Syndrome or Autistic Spectrum Disorder (ASD)	18 (33%)	7 (17%)	80 (51%)	105 (41%)
m) Palliative care needs	1 (2%)	1 (2%)	4 (3%)	6 (2%)
n) Mental health needs e.g. depression, anxiety	8 (15%)	13 (31%)	34 (22%)	55 (22%)

Table 5: Areas of Need by School Level

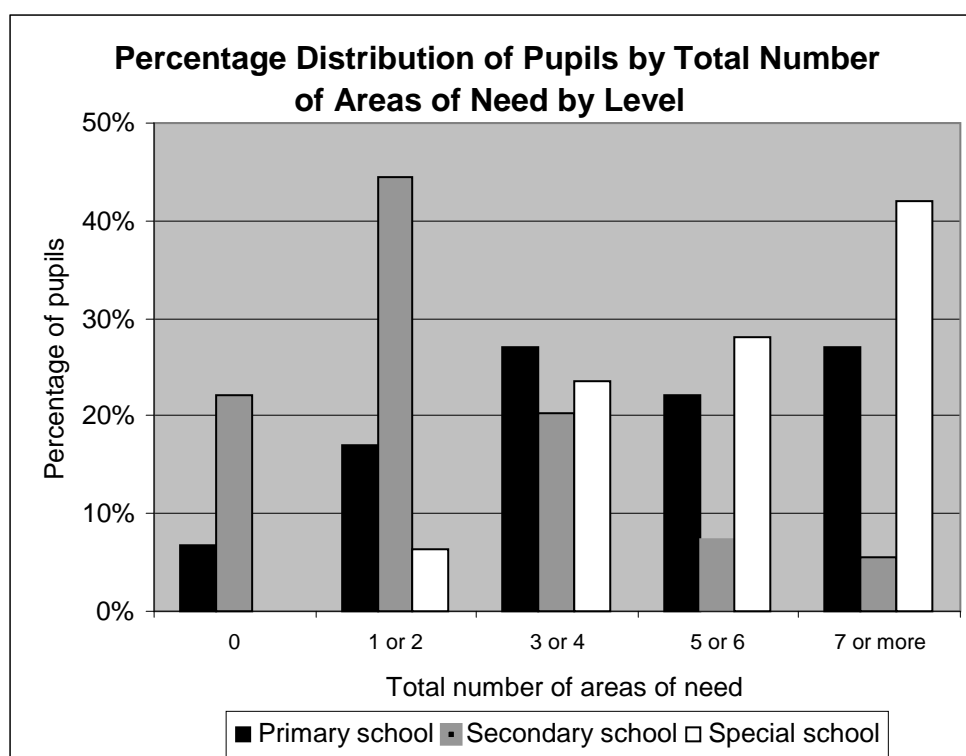


Figure 1: Distribution of pupils by level and need

On the questionnaire his parents indicated that his condition was long standing and that it frequently gave rise to difficulties in participating in activities outside the classroom in school and outside the home.

'He finds it hard to walk effectively. He has numb feet and ankles and constant foot ulcers and trauma to his feet. His poor circulation causes slow healing'

They stated that he had no support in school and that he is unable to do contact sports such as rugby, football or running because of the risk of trauma to his feet & ankles & his extremely delicate spine. They wrote that he has to stand or sit and watch, and isn't given alternative activities. The young person had been seen by a doctor, a paediatrician, a neurosurgeon and a physiotherapist.

His observed engagement in class was problematic. He was intermittently engaged in the classroom tasks and appeared to have difficulty in discerning exactly what it was he was supposed to be doing. His teacher suggested that he was easily distracted and that he could be frustrated and behave in an erratic manner. He has a record of poor attendance.

The school were aware that he was experiencing difficulties but were not all staff were aware of the exact cause. The school's 'Specific Medical Difficulties' sheet has now been updated and distributed to staff.

Figure 2: Data concerning a “surprise” pupil

